PREDICTORS OF RESILIENCE IN FAMILIES OF ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES FOLLOWING DEINSTITUTIONALIZATION

By

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PREDICTORS OF RESILIENCE IN FAMILIES OF ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES FOLLOWING DEINSTITUTIONALIZATION

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Abstract: The current study utilized the family resilience model (Henry, Morris, & Harrist, 2015) to examine the relationship between empowerment, family member age, family relative number of years institutionalized, and resilience in families of individuals with intellectual and developmental disabilities in order to better understand factors that contribute to family adaptation during transition. Using a sample of 56 family members whose relative with intellectual and developmental disabilities recently experienced state-mandated deinstitutionalization in Oklahoma, three research questions were examined: How are family empowerment and family resilience related; how are family member age and family relative number of years institutionalized related to family resilience; and do demographic variables moderate the relationship between family empowerment and family resilience? The results indicate family empowerment, a hypothesized protective factor, was a significant predictor of family resilience. Additionally, results show family resilience was not predicted by either family demographic variable, nor was there any significant association, positive or negative, between these hypothesized vulnerability factors and family resilience. These results suggest that family empowerment may be a crucial mechanism through which overall positive family adaptation is achieved for families of individuals with intellectual and developmental disabilities. Implications of these findings for future research, policy, and practice are discussed.

TABLE OF CONTENTS

LIST OF TABLES

Table Page

LIST OF FIGURES

Figure Page

CHAPTER I

INTRODUCTION

On November 1, 2012, the Oklahoma Department of Human Services (OK-DHS) passed a resolution to close the two remaining state-funded institutions that were providing care to approximately 240 individuals with intellectual and developmental disabilities (Oklahoma Commission for Family Services, 2012). The closing of these institutions, Northern Oklahoma Resource Center of Enid (NORCE) and Southern Oklahoma Resource Center in Pauls Valley (SORC), marked Oklahoma's subsequent following of a larger national trend toward the best practice of providing community-based services in lieu of institutional care. At the time, over 5,000 people with intellectual and developmental disabilities (IDD) were already being served by OK-DHS to live in the community throughout Oklahoma. In the resolution, the state developed plans to manage the transition for residents of the two institutions.

Oklahoma's deinstitutionalization, much like deinstitutionalization movements in other states and countries, represents a major shift in the way long-term services and supports (LTSS) are provided for individuals with IDD. Family members are the largest providers of care for individuals with IDD in the United States (Rizzolo, Larson, & Hewitt, 2016); as such, deinstitutionalization significantly impacts families as well as the individuals receiving services. Research suggests that many families initially oppose deinstitutionalization (Berry, 1995; Tabatabainia, 2003). In Oklahoma, the Department of Human Services attempted to address this concern through its resolution by involving families in the transition process (Oklahoma

Commission for Family Services, 2012). In addition to the development of plans to support those transitioning from the institutions, OK-DHS also committed to the development of plans to support families during the difficult transition to community living (Oklahoma Commission for Family Services, 2012).

Although individuals leaving NORCE and SORC did not move back into the family home, family members were asked to be the overseers of care as their relatives received residential supports to live in the community. As such, family lifelong caregiving is still present and essential (Jones & Gallus, 2016; Reynolds, Gotto, Agosta, Arnold, & Fay, 2016). Research suggests that family caregivers face unique challenges in their role of supporting family members with IDD. These challenges include extra financial costs, chronic stress, social isolation, and perhaps most importantly, additional responsibilities of navigating multiple social service systems (Agosta, 1999; Agosta & Melda, 1995; Ireys, Chernoff, DeVet, & Young, 2001; King, Teplicky, King, & Rosenbaum, 2004; Thompson et al., 1997).

Deinstitutionalization may be challenging for families and lead to enhanced risk as they navigate new social service systems during and following the transition to community living. However, some families are resilient despite significant risk (Henry, Morris, & Harrist, 2015). As such, it is important to explore both factors that may serve to aid families in positive adaptation as well as factors that may affect the ability of families to positively adapt following significant risk. One growing body of research in family science that seeks to understand what helps families successfully navigate significant risk is resilience theory (Henry et al., 2015).

For families experiencing deinstitutionalization, the ability to adequately care for their family members with IDD in the community relies heavily upon public social service systems; without receiving proper services, families may experience negative outcomes at no fault of their own (Patterson, 2002b). Furthermore, previous research suggests that family members' initial opposition to the concept of deinstitutionalization can be partially explained by concerns of inadequacy of necessary community-based supports (Tabatabainia, 2003). Thus, family

empowerment, the ability to navigate complex social service systems, may provide the mechanism for increasing positive outcomes for families overall. Indeed, both theoretical and empirical evidence suggests that empowerment in families regarding social service networks may play a role in helping both individuals and their families navigate toward better outcomes (Singh et al., 1995). However, additional factors may impact the ability of families to positively adjust to their family member's transition to community living.

A large number of individuals transitioning from institutional care facilities and their family caregivers (i.e., parents, siblings) are among the aging population, the fastest growing demographic in the United States (Rizzolo et al., 2016). In addition, individuals transitioning to integrated community living from Oklahoma's institutions have been residents in large congregate care facilities for decades. Such a transition after long-term residence in institutions initiates changes in long-standing family rituals and routines, utilized by families to reduce stress in times of change (Fiese, 2006). Thus, while family empowerment may serve as a mechanism for families to move toward positive adaptation, the difficulties that caregivers may begin to experience due to aging (Hahn et al., 2016) coupled with the disruption in routines and rituals that families experience after the transition may impact empowerment's effectiveness as a protective factor.

While many studies have been guided by resilience theory, few exist that specifically examine families of individuals with intellectual and developmental disabilities specifically. Although deinstitutionalization has been viewed through the lenses of social ecological theory (Berry, 1995) and family systems theory (Jones & Gallus, 2016), there is limited research on factors influencing family resilience during the move to community living and similar transitions. To address these gaps in literature, protective processes and vulnerability factors will be examined in the context of the family resilience model (Henry et al., 2015) to better understand family resilience during deinstitutionalization. Specifically, three research goals for the current study exist:

1. The first goal is to examine the link between family empowerment (operationalized as having family, social system, and community/political dimensions) and family resilience (operationalized as self-efficacy, optimism, emotional regulation, access to support networks, perceived emotional and social resources, spirituality and religiosity, relational accord, and emotional expression).
2. The second goal is to examine the link between family demographic variables (e.g., family member age, family relative number of years institutionalized) and family resilience.
3. The third goal is to analyze whether family demographic variables (e.g., family member age, family relative number of years institutionalized) moderate the link between family empowerment and family resilience.

CHAPTER II

REVIEW OF LITERATURE

Deinstitutionalization: From Congregate Care to Community Living

Since the 1960s, the number of individuals with intellectual and developmental disabilities (IDD) living in large congregate care facilities in the United States has declined by 85% (Larson et al., 2014). Although the overall reduction has occurred over a period of several decades, there has been a steep decline in the past seven years (Larson et al., 2014; Larson, Ryan, Salmi, Smith, & Wuorio, 2012). The number of individuals living in public residential facilities in the U.S. decreased from 35,035 in 2008 to 27,440 in 2012—a decline of nearly 7,600 people in a period of only four years (Larson et al., 2014; Larson, Ryan, Salmi, Smith, & Wuorio, 2012). By 2012, 13 states reported no large state-run facilities in operation while an additional nine states reported plans to close another 14 by 2020 (Larson et al., 2014) This large, recent shift to community living illustrates that although the deinstitutionalization movement began over 50 years ago, it remains a current issue (Jones & Gallus, 2016; Larson et al., 2014).

Several factors have contributed to the shift from institutional care to community living (Larson & Lakin, 1989). In the 1960s and 1970s, concerns regarding living conditions inside institutions led to both deinstitutionalization and a push for institutional reform (Larson & Lakin, 1989). Another move toward community living was the introduction of the Medicaid Home and Community-Based Services program (HCBS) that provides funding for community supports and

thus allows individuals with IDD to live in their communities (Hewitt, Nord, Bogenshut, & Reinke, 2013). State and federal policies originally directed toward institutional reform increased the overall cost of maintaining institutions; in some cases, non-compliance resulted in mandated closures (Conroy & Bradley, 1985; Tossebro, 1998).

Additional factors contributing to the deinstitutionalization movement include the benefits for individuals with intellectual and developmental disabilities. In their 2013 study, Larson, Lakin, and Hill reported significant improvements in adaptive behavior among individuals with IDD including academic skills, community living skills, self-care skills, communication skills, motor/physical skills, and vocational skills following the move from an institution to the community. In a 2015 statement, the Association of University Centers on Disabilities (AUCD) and the American Association on Intellectual and Developmental Disabilities (AAIDD) reported increased self-determination, larger social networks, increased acceptance from other community members, and higher overall satisfaction among individuals with IDD who live in community-based settings (AUCD & AAIDD, 2015; Kozma, Mansell, & Beadle-Brown, 2009; Larson, Lakin, & Hill, 2013). Although community living has been shown to be the best practice for individuals with IDD, initial opposition to deinstitutionalization by families of individuals with IDD remains prevalent (Berry, 1995; Heller, Bond, & Braddock, 1988; Jones & Gallus, 2016; Larson & Lakin, 1991; Tabatabainia, 2003; Tossebro & Lundeby, 2006).

Deinstitutionalization and Families

In 1991, research showed that 91.1% of parents were satisfied with the institutional care that their son or daughter received and 74.2% of parents were opposed to the move to community living (Larson & Lakin, 1991). Although the data show that this opposition to deinstitutionalization does shift to satisfaction with community living over time (Berry, 1995; Conroy & Bradley, 1985; Jones & Gallus, 2016; Larson & Lakin, 1991; Tabatabainia, 2003;

Tossebro & Lundeby, 2006), it is important to understand why families of individuals with IDD may oppose the deinstitutionalization movement.

Understanding the reasons families chose institutional care initially may provide insight into families' opposition to deinstitutionalization. The institutional model of care for individuals with IDD peaked in the mid-20th century; while research suggested that the initial decision to institutionalize was not an easy one (Berry, 1995; Tabatabainia, 2003), it also indicated that institutional care was often the best choice for many families and was encouraged by professionals at the time (Berry, 1995). Furthermore, national policies, funding, and cultural norms and values suggested institutional placement as the right choice for people with IDD; families who chose to keep their child at home were "as likely to be criticized as praised" (Berry, 1995, p. 380).

Many families who chose to keep their children at home struggled to gain access to the services they needed for their children. They were denied admission to public schools, unable to access expensive therapy services or adequate health care, and unable to secure appropriate childcare (Berry, 1995). Social stigma led to isolation of families as support from employers, neighbors, and even extended family was scarce. Family stress was chronic (Berry, 1995; Tabatabainia, 2003). Relationships within the family system were affected with research indicating lower marital quality and high sibling stress in some cases (Berry, 1995). While the decision to institutionalize was often a painful one, institutions promised the safety, access to medical care, and protection from social stigmas that families wanted for their loved ones (Berry, 1995).

Although the field of IDD underwent an ideological shift from a deficit model to a strengths-based approach (Schalock, 2013) as well as an operational shift in the way services were provided (Hewitt, Agosta, Heller, Williams, & Reinke, 2013), families of individuals living in institutions may have been unaware of the changes (Jones & Gallus, 2016) and thus unaware of opportunities that awaited their family members outside institutional walls. This lack of

knowledge regarding community living may have contributed to families' opposition to deinstitutionalization initially. Research suggests that families opposing the shift to community living prior to the transition resist due to anticipation of inadequate community-based services, adverse impacts on themselves and their family members, and provision of good services by the institution (Tabatabainia, 2003). While these reasons are similar to the reasons families' chose institutions when their family relative was young, one major difference that could contribute to family outcomes lies in the responsibility of care for their family member after the transition: when choosing institutionalization, provision of services by professionals was guaranteed after the move. Families were strongly discouraged from visiting their family members and urged to "get on with their lives" (Berry, 1995, p. 380). Conversely, in mandated deinstitutionalization, family members accept more responsibility as legal guardians of their relative with IDD. In Oklahoma, families were asked to become overseers of their relatives' care in the community and to be actively involved in making choices regarding where their relative would live. This reliance on public programs and increased need to oversee their relatives' care may explain families' dissatisfaction with deinstitutionalization during and immediately following the transition.

Research conducted on families' needs during deinstitutionalization shows that families valued respect of their relative's history, collaboration, provision of consistent and high quality care, inclusion of their relative in the community, and being treated as family first instead of being treated as professionals (Jones & Gallus, 2016). These desires regarding social support programs illustrate both the frequent interaction between families and the social programs in which they must operate as well as the challenges that deinstitutionalization presents to the family system. Because future transitions may still loom for many individuals with IDD in states that vary widely on type, availability, and provision of supports and services and because family members are the greatest resource for individuals with IDD (Berry, 1995), it is important to explore factors of the family system that may provide protection against the disruption and

adversity that significant life changes, such as deinstitutionalization, often create as well as factors that may inhibit families' movement toward positive adaptation.

Resilience Perspectives

One theoretical perspective that seeks to examine these family factors is family resilience theory (Henry et al., 2015). Family resilience perspectives, formed out of an integration of ideas from family systems, family stress theory, and individual resilience perspectives, explores family functioning processes and describes the process by which families adapt and function following exposure to significant risk (Hawley & DeHaan, 1996; Henry et al., 2015; Patterson, 2002b). Therefore, this approach goes beyond exploring individual characteristics and toward examining relational patterns that are crucial to understanding family-level processes and outcomes in response to adversity (Black & Lobo, 2008). In addition, resilience perspectives are multidimensional; because of this, research in the field provides two primary approaches to understanding family resilience: resilience as an outcome and resilience as a process (Patterson, 2002a). Conceptualizing resilience as a process that changes over time and under different conditions instead of as a fixed trait allows for the exploration of resilience in families undergoing mandated deinstitutionalization with the understanding that otherwise successful families may experience decline in performing functions under these conditions.

Family resilience perspectives also allow for the view of families as systems that interact with individual members of the family, subsystems (i.e., parent-child, sibling, or marital dyads), and both proximal and distal ecosystems (i.e., the community, the state; Henry, Hubbard, Struckmeyer, & Spencer, in press). Family system theory posits that families are systems; as such, the parts that make up the system are interrelated and interdependent (Constantine & Whitchurch, 1993). Because of this interdependence, components within the system exhibit mutual influence; in other words, circumstances or events that affect one member of the family also affect each of the other family members and the entire family system overall (Constantine & Whitchurch, 1993). Within this systemic framework, families perform functions, achieve goals,

and participate in interaction patterns that influence positive adaptation, referred to as bonadaptation, or negative adaptation, referred to as maladaptation (Henry et al., 2015). Thus, capabilities of the family are considered in the context of their demands and of the surrounding environment, known as family-ecosystem fit (Patterson, 2002a). To determine family resilience, three criteria have been established: competence in accomplishing at least one family-level outcome, presence of risk leading to the expectation of failure in achieving the outcome, and identifying protective mechanisms that may prevent a poor outcome (Patterson, 2002b).

Family-level outcomes. Family-level outcomes can be conceptualized by evaluating the family's ability to perform four core functions that provide benefits to both individual family members and society (Patterson, 2002a). These four core functions are as follows: membership and family formation; nurturance, education, and socialization; economic support; and protection of vulnerable members (Patterson, 2002a). Mechanisms in which the membership and family formation function benefits individuals are the provision of a sense of belonging, personal and social identity, and the provision of meaning and direction for life (Patterson 2002a). Examples of positive family level outcomes for this function are maintenance of the family unit; a negative outcome could be divorce (Patterson, 2002a). It is important to note that the underlying mechanisms of this function most likely differed for families with at least one member institutionalized; with the move to community living, these families may also experience disruptions to fulfilling the membership function and may be prone to negative outcomes.

At the individual level, the nurturance, education, and socialization function provides for the social, emotional, cognitive, physical, and spiritual development of individual family members while also instilling cultural values and norms (Patterson, 2002a). At the societal level, preparing and socializing individuals to be productive members contributes to the overall well-being of society and protects it from harmful antisocial behavior (Patterson, 2002a). Positive family level outcomes include family love and mutual support, commitment to the marital relationship, and secure attachments; negative family level outcomes are domestic violence and

child abuse (Patterson, 2002a). For families with institutionalized members, nurturance, education, and socialization function for one member may have been primarily carried out by the institutions. Thus, the shift to community living presents new challenges to fulfilling this function for families overall.

The economic support function allows for the provision of food, shelter, and other basic resources necessary for individual growth and development. Positive family level outcomes for this function are adequate food and safe housing whereas negative family outcomes are child neglect and homelessness (Patterson, 2002a). Deinstitutionalization changes how these resources are provided for individuals with IDD; as such, the transition to the community introduces uncertainty for families attempting to fulfill this function for their family member with ID.

The fourth family function, protection of vulnerable members, benefits individuals by providing protective care for children, people with chronic illnesses, or people with disabilities; for society, this function minimizes public authority for the care of people of vulnerable populations. Positive family level outcomes are familial care of children with disabilities; negative outcomes include elder abuse or institutionalization of a family member with a disability (Patterson, 2002a). However, during the peak of institutionalization in the mid-20th century, families of those with IDD were encouraged to place their loved ones in institutions in order to protect them. Thus, with the shift to community living from congregate care, the legal family guardians of family members with IDD must establish the goal of protecting vulnerable members in a new way.

This abrupt change in all four family functions could create a mismatch between families' demands (or risk factors) and capabilities (or protective factors) resulting in disruption or crises within the family system (Patterson, 2002b). While the shift to community living introduces challenges to fulfilling the functions of membership and nurturance, fulfilling the functions of both economic support and protecting vulnerable family members is achieved primarily through public programs and policies that ensure access to important services formerly

provided by the institution. Thus, public resources shape the manner and extent to which families are able to fulfill these functions (Patterson, 2002b). The absence of or inadequacy of these services, such as healthcare, employment, and residential provision, contributes to high-risk status and undermines family resilience overall (Patterson, 2002b).

Presence of risk. Another criterion for determining a family's resilience is establishing the presence of significant risk that may lead to failure in achieving the outcome. It should be noted that from this perspective, only those who experience significant risk may be identified as resilient (Patterson, 2002b). Significant risk is defined as more than daily life challenges; rather, significant risk develops from either exposure to traumatic events or adversity, "continuous, chronic exposure" (Patterson, 2002b, p. 237) to unfavorable or hostile social environments, or a combination of the two conditions (Patterson, 2002b). Deinstitutionalization can be considered significant risk as a result of both conditions. As previously established, deinstitutionalization causes a disruption in all four family functions. The adversity introduced to families as a result of this single event classifies deinstitutionalization as significant risk. However, deinstitutionalization can also be considered significant risk as a result of continued exposure to unfavorable social environments.

Individuals transitioning to the community have lived in institutions for decades. While the institutions provided resources and care for individuals, they did not provide environments that fostered social inclusion, which has been shown to promote individual development by increasing self-esteem, confidence, decision-making, and well-being while also decreasing negative outcomes (Simplican, Leader, Kosciulek, & Leahy, 2015). As such, institutional environments were not conducive to promoting positive individual development, which can have lasting impacts. The long-term effects of this can be best understood first in terms of developmental cascades, or cumulative effects of development over time, and then by understanding those cascades in the context of the family system.

Developmental cascades are the collective effects of development over time and impact resilience by altering the course of individual development (Masten & Cicchetti, 2010). These developmental cascades are systemic and fluid; the effects spread to different levels (i.e., individual to family), different domains within the same level (i.e., self-determination to loneliness), different generations (i.e., grandmother to granddaughter), and across systems (i.e., the family system to the educational system; Masten & Cicchetti, 2010). Cascades can be positive or negative with respect to the influence they have on adaptive behavior and propose that failures in developmental tasks, the major tasks of adaptation across the lifespan (Masten & Coatsworth, 1998), have negative influence on other life domains (Masten & Cicchetti, 2010). Conversely, success in developmental tasks promotes future competence (Masten & Cicchetti, 2010).

Because developmental cascades occur over time, interventions or significant events could interrupt and refocus the direction of cascades. While moving a child with IDD from their home to an institution can be a traumatic event, it may also limit opportunities for successful completion of developmental tasks such as attachment to caregivers, language, following societal rules of moral behavior, prosocial conduct, school adjustment, and forming self-identity (Masten & Coatsworth, 1998). Failure to achieve these early developmental tasks as a result of institutionalization may create negative developmental cascades for individuals and thus lead to more negative outcomes during later life events (such as deinstitutionalization), increasing the risk for trauma and adversity.

Understanding developmental cascades within the family system provides insight into significant risk within and across the family system (Henry et al., 2015). How individual developmental cascades affect the family is best understood in the framework of family system theory, a grand theory from which family resilience perspectives is formed. Because of the mutual influence inherent in family systems, negative developmental cascades that produce negative outcomes for individuals would also have negative impact on family resilience overall. In addition, these family cascades can occur at multiple levels and can be triggered by new

stressors or traumatic events. While the likelihood of a cascade of additional risks increases when there are insufficient protective factors (Patterson, 2002b), the inverse is also true: protective mechanisms in one family subsystem may prevent negative cascades or stop them once they have begun even if they are present in another subsystem (Henry et al., 2015).

Protective mechanisms. The last criterion for determining a family's resilience is identifying protective mechanisms that may prevent poor outcomes. In seminal research on resilience and protective mechanisms, Rutter (1987) describes the need for understanding protective mechanisms operating at times when risk trajectories can be redirected onto more adaptive paths. Because variables can be detrimental in one condition yet advantageous in another, protective factors must be viewed in the context of risk and vulnerability (Rutter, 1987). One theoretical model that seeks to understand these protective factors in the context of risk, vulnerability, and adaptation across systems is the family resilience model (Henry et al., 2015).

The Family Resilience Model

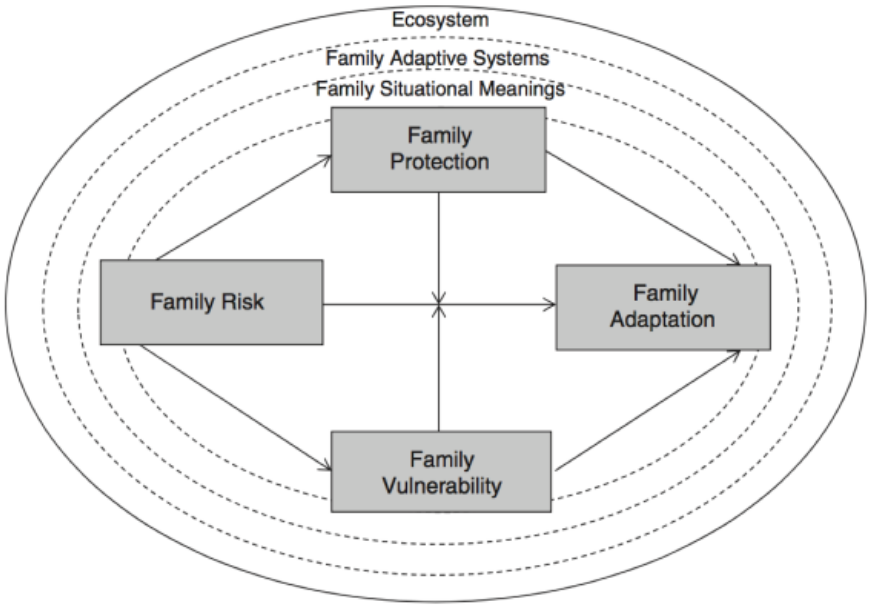
The family resilience model identifies elements that, when examined in the context of family situational meanings, adaptive systems, and the larger ecosystem, describe resilience processes within families (see Figure 1; Henry et al., 2015). The interaction of these four elements—family risk, family protection, family vulnerability, and adaptation—provide insight into families who are displaying resilience (conceptualized as interactions of risk, protective factors, and vulnerability factors that result in positive family adaptation) and those who are not (conceptualized as interactions of risk, protective factors, and vulnerability factors that result in negative family adaptation; Henry et al., 2015).

Significant family risk is defined as a combination of stressors, resources, and perceptions that disrupt family functioning and increase the potential for negative family outcomes (Henry et al., 2015). As previously established, deinstitutionalization introduces significant risk to families of those transitioning from congregate care to community living. To

determine whether this significant risk contributes to positive or negative family adaptation, both protective factors and vulnerability factors must be considered.

Figure 1

Family Resilience Model



Note: This figure is used with permission from Wiley and Sons Publishing and originally appears in Henry et al., 2015.

In this model, protective processes are defined as family resources that modify risk, minimize negative cascades, and promote competence despite significant risk while vulnerability is described as situations in which families are more likely to experience adversity associated with risk (Henry et al., 2015). Because deinstitutionalization introduces significant risk to families of those transitioning from congregate care to community living, it is important to understand what protective and vulnerability factors contribute to family resilience following the transition to community living while also keeping in mind families' necessary reliance on social programs.

Protective factors. One way to understand family protective processes in the context of public social programs is by examining family empowerment. Family empowerment has been

broadly defined as "…the ongoing capacity of individuals or groups to act on their own behalf to achieve a greater measure of control over their lives and destinies" (Koren, DeChillo, & Friesen, 1992, p. 308). Further defined, empowerment is the process by which families access knowledge, skills, and resources that enable them to gain positive control of their lives (Singh et al., 1995). The empowerment construct consists of two dimensions: the level of family empowerment and the way family empowerment is expressed (Koren et al., 1992).

Empowerment in families occurs at three main levels: the family, the service system, and the community/political levels. Together, these levels contribute to management of daily life tasks, working with social programs to receive needed services, and advocacy for improved services for individuals overall (Koren et al., 1992). In addition, empowerment can be expressed in three ways: attitudes, knowledge, and behaviors. The feelings, beliefs, knowledge, potential actions, and actual actions reflected in these three expressions of empowerment can occur across levels of empowerment (Koren et al., 1992). Collectively, these two dimensions provide insight into how families influence their social environments to promote positive outcomes and higher quality of life (Singh et al., 1995). Research into positive outcomes associated with empowerment suggest that empowerment is related to lower levels of stress and higher levels of family functioning, education, employment, mental health status, and family involvement, among others (Resendez, Quist, & Matshazi, 2000).

For families of individuals with IDD moving from institutions to community settings, knowledge of and gaining access to public social resources for their family members could be essential in promoting positive adaptation and overall family resilience; however, vulnerability factors could influence the effect of empowerment on adaptation. Thus, it is important to include these factors to more adequately understand resilience processes in families experiencing mandated deinstitutionalization.

Vulnerability factors. For families experiencing deinstitutionalization in Oklahoma, additional demands are faced in the context of an aging population of caregivers. While

individuals transitioning from institutions to the community may not move into the family home, family caregivers provide emotional, financial, nursing, social, homemaking, and a variety of other services on a daily or intermittent basis (Talley & Montgomery, 2013).

Family caregiving for individuals with IDD is a lifelong reality, increasing the probability that caregivers will experience distress, or caregiver burden. Caregiver burden refers to the physical, emotional, psychological, social, and financial problems that family caregivers experience. It is triggered by the strain of care tasks and restriction of daily tasks (Given, Given, Sherwood, & DeVoss, 2013) and can add vulnerability to a family's overall resilience process. In addition, caring for family members in mid- and late-life presents unique challenges. As caregivers age, rates of health and mental health difficulties increase, further adding to the difficulties that accompany prolonged caretaking for adults (Heller, Gibbons, & Fisher, 2015) and increasing family vulnerability.

Another factor that may enhance family vulnerability during deinstitutionalization and thus impact protective factors and overall family resilience is the number of years a family member has been institutionalized. Family routines and rituals, utilized by families for meaning-making and therapeutic interventions (Fiese, 2006) are likely to be long-standing and entrenched in the older, long-established families who undergo the transition of their family member from institutions to the community. Deinstitutionalization introduces a disruption to both routines and rituals which may be more harmful in families who have utilized the same routines and rituals for an extended period of time (i.e., families with a family member who has lived in an institution for a longer number of years; Jones & Gallus, 2016).

Current Study

While resilience perspectives have been applied to many areas of study, they have not been broadly applied in the field of IDD. In addition, research on the relationships between protective factors and resilience and the impact of vulnerability factors on that relationship during deinstitutionalization has not been conducted. To address these gaps in literature and better

understand relationships between factors which theoretically impact family adaptation following deinstitutionalization, the family resilience model will be used. Specifically, the following research goals and hypotheses exist for the current study:

Research Question 1. How are family empowerment and family resilience related?

Hypothesis 1: Total family empowerment will be positively and significantly associated with total family resilience.

Hypothesis 2: Family empowerment will be a significant predictor of family resilience.

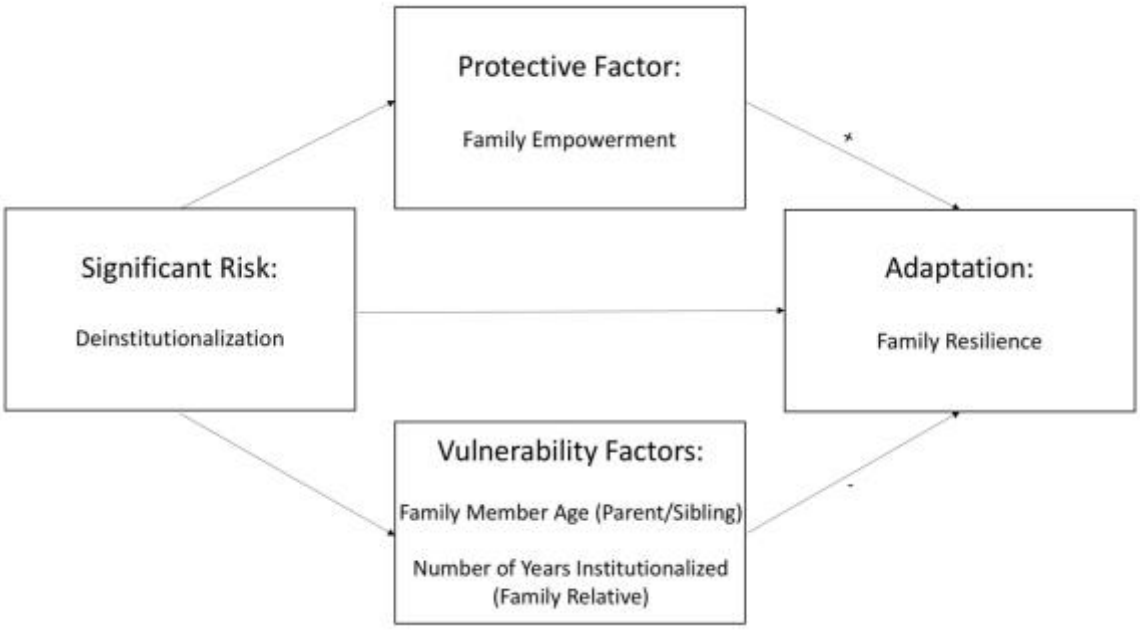
Research Question 2. How are family member age and family relative number of years institutionalized related to family resilience?

Hypothesis 3: Family member age will be negatively and significantly associated with total family resilience.

Hypothesis 4: The number of years a family relative with ID has been institutionalized will be negatively and significantly associated with family resilience.

Figure 2

Hypothesized relationships between protective factors, vulnerability factors, and family adaptation following deinstitutionalization



Note: Family resilience model core (Henry et al., 2015), adapted.

Research Question 3. Do demographic variables moderate the relationship between family empowerment and family resilience?

Hypothesis 5: The association between family empowerment and family resilience will be attenuated for participants reporting older ages but will be significant for those reporting younger ages.

Hypothesis 6: The association between family empowerment and family resilience will be attenuated for participants reporting higher number of years institutionalized but will be significant for those reporting fewer years institutionalized.

Figure 3

Hypothesized moderation effect of family member age

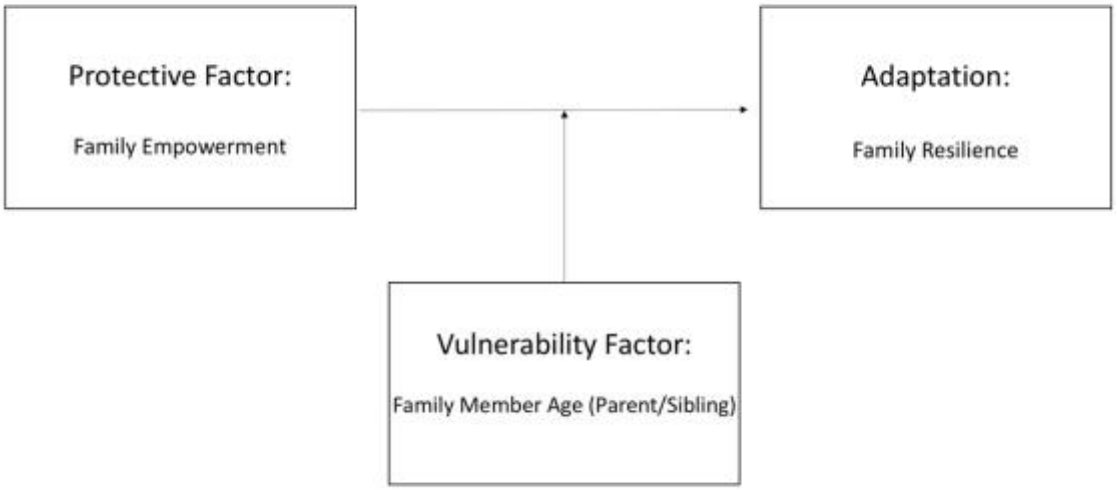
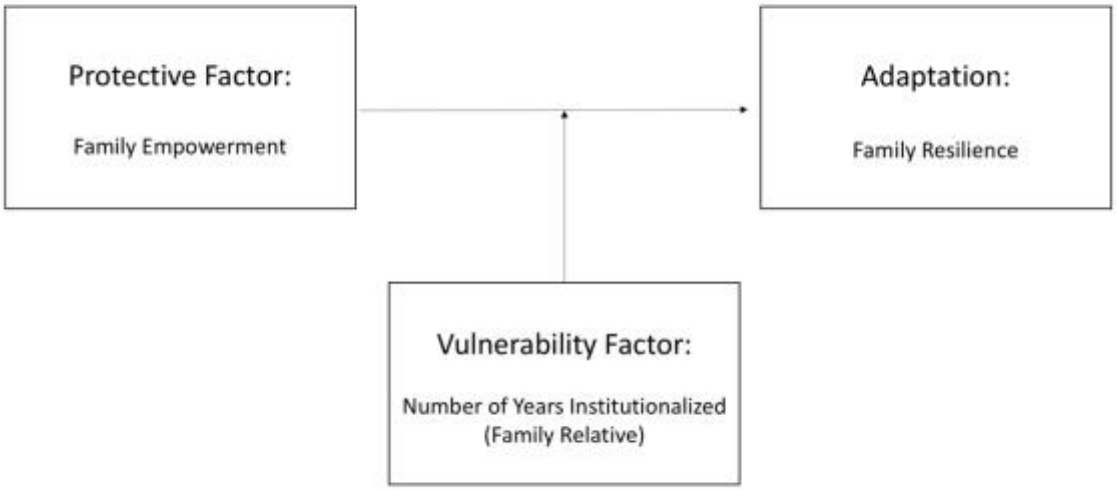


Figure 4

Hypothesized moderation effect of family relative number of years institutionalized



CHAPTER III

METHODOLOGY

Both quantitative and qualitative data were collected as part of a large mixed-methods study by a team of faculty members, Drs. Jennifer Jones & Kami Gallus, and graduate students at Oklahoma State University (OSU) in order to better understand families' experiences during the mandated transition of their relative from institutional care to community living in Oklahoma. Data for Phase I (quantitative surveys) and Phase II (qualitative interviews) were collected between January and May 2015. All family members in both phases of the study had full legal guardianship of their relative with intellectual and developmental disabilities. For the current study, only quantitative data from Phase I was utilized.

General Procedures

Permission to conduct the original study was granted by the OSU Institutional Review Board (IRB) and supported by the Oklahoma Department of Human Services—Developmental Disability Services division (OKDHS-DDS), who provided the research team with a list of 153 legal family guardians of individuals transitioning out of state institutions and their contact information. Family guardians living outside of the state of Oklahoma were removed from the sampling frame prior to recruitment for consistency in sampling the target population (i.e., Oklahoma residents). Participants were then recruited to Phase I by letters of invitation and informed consent as well as quantitative surveys mailed to their homes. While documentation of consent was waived for additional protection of participant confidentiality, individuals indicated

consent by their willingness to complete the survey. Of 135 the surveys mailed, 56 were completed and returned via self-addressed stamped envelopes provided to the participants with the study materials. Permission to conduct secondary data analysis for the current study was granted by the OSU IRB.

Participants

Participants in Phase I included 56 family members. Of these, 48.2% were mothers or step-mothers (*n* = 27), 28.6% were sisters (*n* = 16), 16.1% were fathers (*n* = 9), and 7.1% were brothers (*n* = 4). Family members ranged in age from 39 to 89 years of age (*M* = 66.7, *SD* = 9.9). Family members' race/ethnicity included 80.4% European American (*n* = 45), 12.5% American Indian or Alaska Native (*n* = 7), 3.6% African American (*n* = 2), 1.8% Hispanic or Latino (*n* = 1), and 1.8% Asian or Pacific Islander (*n* = 1). Table 1 includes additional family member demographic information. Family relatives with IDD ranged in age from 35 to 66 years (*M* = 50.3, *SD* = 8.5). The number of years that family relatives lived in institutional settings ranged from 22 to 62 years (*M* = 42.3, *SD* = 8.7). Table 2 includes additional family relative demographic information.

Table 1

Demographic information: Family members (N = 56)

	Mean	SD	Range
Age	66.77	9.88	39.00 – 89.00
		N	%
Gender			
Female		43	76.8
Male		13	23.2
Relationship to Relative with IDD			
Mother/Step-Mother		27	48.2
Father		9	16.1
Sister		16	28.6
Brother		4	7.1
Race			
American Indian/Alaska Native		7	12.5
Hispanic/Latino		1	1.8
Asian/Pacific Islander		1	1.8
European American		45	80.4
African American		2	3.6
Marital Status			
Married		29	51.8
Widowed		13	23.2
Divorced		13	23.2
Separated		1	1.8

Table 1

Continued

	N	%
Highest Level of Education		
No Schooling Completed	1	1.8
Grade School to 8th Grade	2	3.6
High School Graduate or Equiv.	10	17.9
Vocational Training	7	12.5
Some College	12	21.4
Associate Degree	4	7.1
Bachelor's Degree	9	16.1
Master's Degree	7	12.5
Doctorate Degree	4	7.1
Employment Status		
Employed Full-Time	12	21.4
Employed Part-Time	4	7.1
Unemployed	2	3.6
Unemployed (Due to Disability)	4	7.1
Retired	33	58.9
Full-Time Homemaker	1	1.8
Income		
Below $9,999	1	1.8
$10,000 - $19,999	10	17.9
$20,000 - $29,999	11	19.6
$30,000 - $39,000	3	5.4
$40,000 - $49,000	3	5.4
$50,000 - $59,000	4	7.1
$60,000 - $69,000	3	5.4
$70,000 - $79,000	3	5.4
$80,000 - $89,000	3	5.4
$90,000 - $99,000	2	3.6
$100,000 – Above	6	10.7
Health		
Poor	5	8.9
Fair	14	25.0
Good	30	53.6
Excellent	7	12.5

Table 2

Demographic information: Family relatives (N = 56)

	Mean	SD	Range
Age	50.26	8.48	35.87 – 66.26
Number of Years Institutionalized	42.30	8.67	22.00 – 62.00
		N	%
Gender			
Female		17	30.4
Male		38	67.9
Race			
American Indian/Alaska Native		2	3.6
Hispanic/Latino		1	1.8
Asian/Pacific Islander		0	0.0
European American		50	89.3
African American		2	3.6
Other		1	1.8
Level of ID			
Moderate ID		1	1.8
Severe ID		11	19.6
Profound ID		43	76.8

Measures

Demographics. Participants completed a 14-item demographic information survey after completing the resilience and empowerment measures described below. Family members reported their age (in years), gender, relationship to family relative, marital status, race, and level of education as well as employment status, income, and health information. Gender was coded dichotomously as "Male" = 1 and "Female" = 2. Relationship to family relative was coded as "Mother" = 1, "Father" = 2, "Sister" = 3, "Brother" = 4, "Aunt" = 5, "Uncle" = 6, "Cousin" = 7, "Stepmother" = 8. Family members' marital status was coded as the following: "Never married" = 1, "Married" = 2, "Widowed" = 3, "Divorced" = 4, "Separated" = 5. Family members' race was coded as "American Indian or Alaska Native" = 1, "Hispanic or Latino" = 2, "Asian or Pacific Islander" = 3, "European American (white)" = 4, "African American (black)" = 5, and "Other" = 6. Family members' level of education was coded as "No schooling completed" = 1, "Grade school to 8th grade" = 2, "Some high school, no diploma" = 3, "High school graduate, diploma, or equivalent GED" = 4, "Trade/technical/vocational training" = 5, "Some college credit, no degree" = 6, "Associate degree" = 7, "Bachelor's degree" = 8, "Master's degree" = 9, and "Doctoral degree" = 10. Family members' employment status was coded as "Employed full-time" = 1, "Employed part-time" = 2, "Unemployed" = 3, "Unemployed (due to disability)" = 4, "Retired" = 5, "Full-time student" = 6, "Part-time student" = 7, and "Full-time homemaker" = 8. Income was coded categorically as well: "Below $9,999" = 1, "$10,000-$19,999" = 2, "$20,000-$29,999" = 3, "$30,000-$39,999" = 4, "$40,000-49,999" = 5, "$50,000-$59,999" = 6, "$60,000-$69,999" = 7, "$70,000-$79,999" = 8, "$80,000-$89,999" = 9, "$90,000-$99,999" = 10, and "$100,000-above" = 11. Family members' health was coded as "Poor" = 1, "Fair" = 2, "Good" = 3, and "Excellent" = 4.

In addition to these items, family members were also asked to provide information about the residential history of their family relative. All family relatives in the current sample were also participants in the National Core Indicators (NCI) Project. As a result, family relative

demographic information was assessed as part of the NCI Adult Consumer Survey. This survey was designed to assess performance and outcomes of individuals with developmental disabilities in order to improve state developmental disability services (Havercamp, Scandlin, & Roth, 2004). Family members in the present study were given the same identification number as their family relative in the NCI records prior to analyses. Family members were informed that their consent to participate in the study included linking family relative and family member data. Permission to use this data was granted by OK-DHS DDS and the NCI principal investigators, Dr. Jennifer Jones and Dr. Kami Gallus.

Family Empowerment. Family empowerment was assessed using the Family Empowerment Scale (FES), a 34-item rating scale developed to measure levels of empowerment in families with children with emotional, behavioral, or mental disorders and shows promise for use with families whose children have a disability (Singh et al., 1995). The FES measures empowerment on a five-point Likert scale that taps into empowerment at three levels: family, service system, and community/political. Subscale scores are the sum of the respective item scores: scores on the family and service system subscales range from 12 to 60 (Singh et al., 1995). Scores on the community/political subscale range from 10 to 50 (Singh et al., 1995). Total scale scores are the sum of all items. For each subscale and for the total scale, higher scores reflect more empowerment. Sample items include *"I feel that my knowledge and experience as a parent can be used to improve services for children and families," "I have a good understanding of the service system that my child is involved in," "when faced with a problem involving my child, I decide what to do and then do it,"* and *"I feel that I have a right to approve all services my child receives"* (Singh et al., 1995). The FES reports adequate reliability, with internal consistency ranging from .87 to .88. and test-retest reliability ranging from .77 to .85 (Koren et al., 1992). Reliability (Cronbach's alpha) for the current study ranges from .77 to .90 with adequate reliability overall (.88).

Family Resilience. Family resilience was assessed using the 22-item Multidimensional Individual and Interpersonal Resilience Measure (MIIRM, Martin, Distelberg, Palmer, & Jeste, 2014). The MIIRM was developed to measure individual and family resilience in a population of older adults (aged 50-99 years) and includes eight dimensions: self-efficacy, access to support networks, optimism, perceived economic and social resources, spirituality and religiosity, relational accord, emotional expression and communication, and emotion regulation (Martin et al., 2014). Responses to items on the MIIRM are reported on a Likert scale. A total score was calculated by adding up all of the items. Subscale scores are the sum of the respective items (some subscales were reverse-scored; see Table 8; Martin et al., 2014). Higher scores reflect higher levels of resilience while lower scores indicate lower levels of resilience (Martin et al., 2014). Sample items include *"I am able to adapt to change," "Overall, I expect more good things to happen to me than bad," "How satisfied are you with your finances?" "How often do you feel lonely?" "How often do your spouse, children close friends make too many demands on you?"* and *"To what extent do you consider yourself a religious person?"* (Martin et al., 2014). The MIIRM reports adequate reliability with internal consistency ranging from .61 to .88 (Martin et al., 2014). Subscale reliability (Cronbach's alpha) in this study ranges from .53 to .87 with adequate reliability overall (.83).

CHAPTER IV

FINDINGS

Data Analysis

First, descriptive statistics were computed for each of the variables and are presented in Table 3. For research questions one and two, a series of bivariate correlations was computed to examine the relationships between the hypothesized protective factor, family empowerment, the hypothesized vulnerability factors, family member age and family relative number of years institutionalized, and the outcome variable of family adaptation, family resilience. To further explore the relationship between age, number of years institutionalized, family empowerment, and family resilience, subscale scores were also included in the correlational analysis.

To examine whether family empowerment is a significant predictor of family resilience, a multiple regression was computed. Family member age, family relative number of years institutionalized, and total family empowerment were entered into the regression simultaneously to determine the amount of unique variance within total family resilience for which each variable is responsible.

To address the last research question, two two-way interactions were entered into the regression (family member age X family empowerment, family relative number of years institutionalized X family empowerment) to determine whether the demographic variables moderate the relationship between family empowerment and family resilience. Evidence of

moderation would exist if a significant interaction was found. In order to reduce nonessential collinearity, main effect variables were centered around the mean prior to the creation of the interaction variables and computing the regression.

Preliminary Analysis

To test for effects in the outcome variable which may result from the type of primary caregiver in the family (parent or sibling), an independent samples t-test was used. Results from the independent samples t-test were not significant, suggesting no group differences in family resilience between families with parent caregivers (M = 82.03, SD = 9.77) and families with sibling caregivers (M = 86.13, SD = 8.04), t (51) = -1.533, p = .132, *ns*. Additionally, no significant differences were found between parents (M = 130.36, SD = 25.24) and siblings (M = 130.43, SD = 17.88) for family empowerment, t(53) = -.011, p = .991, *ns*. As expected, ages of parents (M = 69.81, SD = 9.474) and siblings (M = 61.30, SD = 8.247) were significantly different, t(54) = 3.366, p = .001. Also as expected, family relative number of years institutionalized differed in families with parent caregivers (M = 38.89, SD = 7.85) and sibling caregivers (M = 48.45, SD = 6.44), t(54) = -4.641, p < .001.

Bivariate Correlations

Hypothesis 1. Family member age, family relative number of years institutionalized, family empowerment scale and subscale scores, and family resilience scale and subscale scores were correlated using Pearson product-moment correlation coefficients in order to better understand the relationship between the variables. Total family empowerment was positively and significantly associated with total family resilience, r(54) = .499, p < .01, supporting the hypothesized relationship between the two variables. Thus, families experiencing deinstitutionalization who reported higher levels of empowerment also reported higher levels of resilience, supporting hypothesis 1.

Subscales scores were also correlated to further explore the associations. Family, service system, and community/political empowerment were each positively and significantly associated with the resilience variables of self-efficacy, emotional regulation, and optimism. In addition, perceived resources, a resilience subscale indicating a family's perception of how well their resources currently provide for their needs as well as how well they believe their resources will provide for their needs in the future, was positively and significantly associated with total family empowerment as well as the subscales of family empowerment and service system empowerment. No significant association was found between either family member age or family relative number of years institutionalized and total family empowerment and total family resilience or any of the subscales. Results of the correlational analysis are presented in Table 4.

Regression

Multiple regression analysis was used to test whether family member age, family relative number of years institutionalized, and total family empowerment predict total family resilience. The results of the regression analysis indicate that the set of predictors explained 32.2% of the total variance in family resilience, $R^2 = .322$, (R^2 adjusted = .250), $F(5,47) = 4.473$, $p = .002$. Complete results of the regression analysis are presented in Table 5.

Hypothesis 2. Results show that after controlling for family member age and family relative number of years institutionalized, family empowerment significantly predicted family resilience, (b = .193, $p = .001$). Thus, hypothesis 2 was supported.

Hypothesis 3. A marginally significant effect was found for family relative number of years institutionalized, (b = .239, $p = .077$, *ns*), providing partial support for hypothesis 3.

Hypothesis 4. No main effect for family member age was found (b = .074, $p = .528$, *ns*), providing no support for hypothesis 4.

Hypotheses 5 and 6. To test for moderation effects of family member age and family relative number of years institutionalized, two two-way interactions were entered into the regression analysis. Result of the interactions were as follows: family member age X family

empowerment, b = .000, p = .965, *ns*, family relative number of years institutionalized X family empowerment, b = -.005, p = .445, *ns*. As shown, neither interaction was significant, providing no evidence that moderation exists and thus providing no support for hypotheses 5 and 6.

Post hoc Analysis

Because family member age was not a significant predictor of family resilience, exploratory post hoc regression analysis was completed to determine whether the removal of family member age would also remove variance in family resilience accounted for by the model or if the variance would be reassigned to family relative number of years institutionalized. The results of the analysis indicate that the set of predictors explained 31.6% of the total variance in family resilience, R^2 = .316, (R^2 adjusted = .275), $F(3,49) = 7.562$, $p < .001$, indicating that even after the removal of family member age, the regression model adequately estimates family resilience. As expected, the removal of family member age increased the regression coefficient for family relative number of years institutionalized and allowed for statistical significance, (b = .258, p = .046). Also, as expected, the coefficient for family empowerment was not affected by the removal of family member age. Similarly, the interaction between family relative number of years institutionalized and family empowerment remained nonsignificant (b = -.004, p = .456, *ns*).

Table 3

Descriptive statistics of all factors

	N	Mean	SD
Age (Family Member)	56	66.77	9.88
Number of Years Institutionalized (Family Relative)	56	42.30	8.66
Family Empowerment	55	130.38	22.79
Family Resilience	53	83.42	9.34

Table 4

Correlations

	1	2	3	4	5	6	7	8
1. Family Member Age	-							
2. Number of Years Institutionalized (Family Relative)	.205	-						
3. Total Family Resilience[1]	.099	.239	-					
4. Self-Efficacy[1]	.089	.130	.736**	-				
5. Emotional Regulation[1]	-.030	-.037	.609**	.608**	-			
6. Optimism[1]	-.020	.181	.705**	.448*	.575**	-		
7. Emotional Expression Communication[1]	-.242	-.087	.347*	.138	.037	.123	-	
8. Perceived Resources[1]	.091	.233	.677**	.383**	.258	.218	.070	-
9. Access to Support Network[1]	.168	.177	.333*	.069	-.044	.216	.077	.038
10. Relational Accord[1]	.249	.076	.425**	.399**	.299*	.292*	-.063	.272*
11. Spirituality/Religiosity[1]	.004	.097	.317*	.083	.102	.299*	.188	-.118
12. Total Family Empowerment[2]	-.036	-.035	.499**	.476**	.555**	.482**	-.078	.290*
13. Family Empowerment[2]	-.104	-.036	.513**	.474**	.538**	.463**	-.104	.324*
14. Service System Empowerment[2]	-.046	-.093	.439**	.347**	.455**	.388**	-.070	.317*
15. Community/Political Empowerment[2]	.034	.027	.448**	.476**	.558**	.511**	-.024	.172
Mean	66.77	42.30	83.42	12.86	8.46	11.84	10.76	14.93
Standard Deviation	9.873	8.66	9.34	1.98	1.49	2.28	1.97	4.26
Range	39-89	22-62	65-110	7-15	4-10	6-15	5-15	5-24

Table 4

Continued

	9	10	11	12	13	14	15
1. Family Member Age							
2. Number of Years Institutionalized (Family Relative)							
3. Total Family Resilience[1]							
4. Self-Efficacy[1]							
5. Emotional Regulation[1]							
6. Optimism[1]							
7. Emotional Expression Communication[1]							
8. Perceived Resources[1]							
9. Access to Support Network[1]	-						
10. Relational Accord[1]	-.296*	-					
11. Spirituality/Religiosity[1]	.324*	-.056	-				
12. Total Family Empowerment[2]	.117	.115	.235	-			
13. Family Empowerment[2]	.126	.105	.279*	.951**	-		
14. Service System Empowerment[2]	.186	-.012	.235	.949**	.916**	-	
15. Community/Political Empowerment[2]	.032	.188	.147	.879**	.723**	.720**	-
Mean	12.57	5.51	6.75	130.38	48.05	50.01	32.44
Standard Deviation	2.12	1.55	1.56	22.79	8.12	8.15	8.23
Range	7-16	2-8	2-8	68.8-170.0	26.4-60.0	29-60	12-50

Note: [1]Multidimensional Individual and Interpersonal Resilience Measure, [2]Family Empowerment Scale. $^{**}p < .01$, $^{*}p < .05$. ($n = 56$).

Table 5

Multiple regression analysis of family resilience by Age, Number of Years Institutionalized, and Family Empowerment

	b	SE b	β
Constant	-.038	1.115	
Age (Family Member)	.074	.117	.072
Number of Years Institutionalized (Family Relative)	.239†	.132	.193†
Family Empowerment	.193***	.053	.504***
Age X Family Empowerment	.000	.006	.-106
Years Institutionalized X Family Empowerment	-.005	.006	-.179

Note: ***p < .001, **p < .01, *p < .05, †p < .10

Table 6

Post hoc multiple regression analysis of family resilience by Number of Years Institutionalized and Family Empowerment

	b	SE b	β
Constant	-.006	1.093	
Number of Years Institutionalized (Family Relative)	.258*	.126	.239*
Family Empowerment	.193***	.050	.471***
Years Institutionalized X Family Empowerment	-.004	.006	-.092

Note: ***p < .001, ***p* < .01, **p* < .05

CHAPTER V

CONCLUSION

Previous research suggests that empowerment should be a central focus of services for families of individuals with intellectual and developmental disabilities (IDD) in order to improve outcomes for families (Koren et al., 1992; Resendez, Quist, & Matshazi, 2000; Singh et al., 1995). The results of the present study strongly indicate that, at least for families of adults with IDD experiencing mandated deinstitutionalization, empowerment plays a key role in positive family adaptation. Even after accounting for the age of the family member and the number of years the family relative lived in institutional settings, families' overall level of positive adaptation can be explained in part by their level of family empowerment. Following the move from institutions to the community, families who report higher levels of empowerment are also more likely to report higher levels of resilience than families who do not.

The goal of this study was to empirically test for relationships between family empowerment, family demographic variables, and family resilience based on the family resilience model, which provides a theoretical basis for understanding what contributes to family adaptation in the context of significant risk (Henry et al., 2015). Despite literature suggesting that age of the family caregiver and duration of institutional residence negatively influence families' overall well-being (Fiese, 2006; Griffith & Hastings, 2013; Heller, Gibbons, & Fisher, 2015; Williamson & Perkins, 2014), the present study found that family resilience was not predicted by either hypothesized vulnerability factor, nor was there any significant association, positive or negative, between these factors and family resilience. These findings further illustrate the impact family

empowerment has on well-being: regardless of how old or young the family member is and regardless of how long the family relative has lived away from the community in an institutional setting, a family's ability to navigate the social service system in order to access needed resources for their family relative is essential.

While unique in the use of resilience perspectives to understand family outcomes in the field of IDD, this study supports previous work suggesting that a family's aptitude to act on their own behalf enables them to influence the environments around them and gain positive control over their lives (Koren et al., 1992; Singh et al., 1995; Resendez et al., 2000) and that the magnitude of significant risk is less important than feelings of self-worth, power, and authority over one's life (Bailey & Gordon, 2016). In the case of families of adults with IDD experiencing state-mandated deinstitutionalization, empowerment may be a crucial mechanism through which overall positive family adaptation is achieved.

Findings from the current study supporting family empowerment's role in positive adaptation also elucidates families' negative reactions to mandated transitions overall. Much of the deinstitutionalization literature suggests families' initial opposition to the shift from institutions to the community (Berry, 1995; Heller et al., 1988; Jones & Gallus, 2016; Larson & Lakin, 1991; Tabatabainia, 2003; Tossebro, 1998; Tossebro & Lundeby, 2006); further, previous research with a qualitative subsample of participants in the current study suggests that families desire collaboration and being part of the transition process (Jones & Gallus, 2016). Thus, the finding that family empowerment predicts family resilience is consonant with earlier research on family needs during deinstitutionalization and, taken together, suggests that professionals should recognize the need for empowerment during transition.

Among the methodological strengths of the present study is the use of a theoretical model of resilience as a foundation for both the categorization of variables as factors and the relationship of the predictors to the outcomes. This contributed to the strength of the study by providing a solid framework that highlighted relevant variables and eliminated the inclusion of variables not

likely to be associated with family adaptation. Although the internal validity of the current study is strong, some limitations for external validity do exist and should be discussed. First, although the sample was representative of the population of families experiencing deinstitutionalization in Oklahoma, it was relatively small and fairly homogenous. The majority of the family members in the sample were White females in the aging population; as such, caution should be used when generalizing to other populations. Second, the study utilized a cross-sectional design. In order to better understand factors that both support and inhibit family resilience, future research should utilize longitudinal studies that allow for the examination of resilience trajectories following families' exposure to significant risk. This would better allow for the understanding of resilience processes in families undergoing transitions. Finally, the study utilized single-informant response items at the family level. While this is useful for the current study, future research should employ multi-informant measures to capture processes within families that may contribute to positive adaptation.

Although two of the study's hypotheses received support, the current study did not find that family member age and family relative number of years institutionalized acted as vulnerability factors for these families. As previously noted, the direct, negative association between either family member age and overall family resilience or the number of years a family relative was institutionalized and family resilience was not found as expected. Additionally, the attenuating effect of the vulnerability factors on the relationship between empowerment and resilience was not found as expected. There may be two possible explanations for this. One explanation may be that the effect was present but the limitations presented by the size of the sample did not allow for statistical detection. This explanation is partially supported by the marginally significant effect found for number of years institutionalized.

Another explanation for this may be that the hypothesized vulnerability factors do not negatively affect overall family adaptation in times of significant risk and are not, therefore, vulnerability factors. Support for this explanation can be found in the results of the exploratory

post hoc regression analysis. Because the removal of family member age from the model did not notably decrease the amount of variance in family resilience accounted for by family relative number of years institutionalized and family empowerment, it is reasonable to conclude that family member age is neither a vulnerability factor nor is it relevant for overall family resilience when family empowerment is considered. Support for this explanation can also be found by examining the regression coefficients in the data analysis for both hypothesized vulnerability factors: while neither was statistically significant (at $p < .05$), each coefficient was positive. If the factors truly acted as vulnerability factors, each coefficient should have been negative. This explanation is particularly interesting when examining the positive, marginally significant effect of family relative number of years institutionalized on family resilience, which may suggest that for these families, institutionalization for an extended period of time might have served as a protective factor by providing resources and safety for their family member with IDD. If founded, this would starkly contrast previous resilience literature suggesting that institutionalization is a negative outcome resulting from a family's inability to perform the 'protection of vulnerable member' function (see Patterson, 2002a). Indeed, if considered in the historical context of available supports for community living at the time these individuals entered institutional settings (see Berry, 1995), it is feasible that families in this sample believed institutions provided safety for their family relatives with IDD and, as such, had higher levels of resilience when the relative lived in an institution for a longer period of time. Thus, the finding that neither family member age nor family relative number of years institutionalized acted as vulnerability factors in this study has implications for future research. It may be possible that the effect of institutionalization for individuals with IDD and their families varies depending upon the availability and quality of supports and services in the community. Future research on resilience in families of individuals with IDD during and following significant risk should explore both the timing of transitions as well as families' access to quality community supports.

Findings of the current study also have implications for practice and policy by suggesting that regardless of family member age, empowerment should be a goal of service providers in order to enhance family well-being overall. Practitioners should work to empower families in order to promote better outcomes during times of significant risk across the lifespan. Enhancing empowerment in families can be achieved using a multifaceted intervention approach. First, educational interventions targeted at enhancing families' understanding of the social service system (i.e., Developmental Disabilities Services) should be created in order to inform family members of the services and supports available for their family relatives (see Jones & Gallus, 2016). Additionally, interventions aimed at enhancing families' knowledge of the policies and laws which determine eligibility for services, guardianship, and future planning should be implemented in order to help families take actions best suited for their overall well-being. Finally, interventions should include education on how to work with local, state, and federal legislative representatives in order to encourage families to enact change in the larger system when necessary. By increasing empowerment in families through knowledge, behavior, and attitude interventions, better outcomes for family well-being are possible.

In conclusion, the current study utilized the family resilience model to examine the relationship between family characteristics, empowerment, and resilience in families of individuals with IDD who experienced state-mandated deinstitutionalization in order to better understand factors that contribute to family well-being during times of transition. Perhaps the most important finding of the current study is the role of empowerment as a protective factor for families experiencing the significant risk of major life transitions. A strengths-based approach in the field of IDD requires that both policies and practices function to enhance the existing qualities of individuals and families. This is especially true for families of individuals with IDD in times of significant risk, such as diagnosis, entering and exiting the education system, and the transition to employment. Because individuals and families of individuals with IDD encounter forms of significant risk across the lifespan, it is important that researchers continue to explore factors that

enhance and inhibit overall family adaptation. In doing so, research can provide tools for both policymakers and practitioners in the field of IDD to help families navigate and successfully adapt to risk.

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APPENDICES

Table 7

Family Empowerment Scale (FES)

Below are a number of statements that describe how a parent or caregiver of a parent with an emotional problem may feel about his or her situation. For each statement, please circle the response that best describes how the statement applies to you.

1 = Not true at all
2 = Mostly not true
3 = Somewhat true
4 = Mostly true
5 = Very true

1. I feel that I have a right to approve all services my child receives.	1	2	3	4	5
2. When problems arise with my child, I handle them pretty well.	1	2	3	4	5
3. I feel I can have a part in improving services with children in my community.	1	2	3	4	5
4. I feel confident in my ability to help my child grow and develop.	1	2	3	4	5
5. I know the steps to take when I am concerned my child is receiving poor services.	1	2	3	4	5
6. I make sure that professionals understand my opinions about what services my child needs.	1	2	3	4	5
7. I know what to do when problems arise with my child.	1	2	3	4	5
8. I get in touch with my legislators when important bills or issues concerning children are pending.	1	2	3	4	5
9.I feel my family life is under control.	1	2	3	4	5
10. I understand how the service system for children is organized.	1	2	3	4	5
11. I am able to make good decisions about what services my child needs.	1	2	3	4	5
12. I am able to work with agencies and professionals to decide what services my child needs.	1	2	3	4	5

Table 7

Continued

13. I make sure I stay in regular contact with professionals who are providing services to my child.	1	2	3	4	5
14. I have ideas about the ideal service system for children.	1	2	3	4	5
15. I help other families get the services they need.	1	2	3	4	5
16. I am able to get information to help me better understand my child.	1	2	3	4	5
17. I believe that other parents and I can have an influence on services for children.	1	2	3	4	5
18. My opinion is just as important as professionals' opinions in deciding what services my child needs.	1	2	3	4	5
19. I tell professionals what I think about services being provided to my child.	1	2	3	4	5
20. I tell people in agencies and government how services for children can be improved.	1	2	3	4	5
21. I believe I can solve problems with my child when they happen.	1	2	3	4	5
22. I know how to get agency administrators or legislators to listen to me.	1	2	3	4	5
23. I know what services my child needs.	1	2	3	4	5
24. I know what the rights of parents and children are under the special education laws.	1	2	3	4	5
25. I feel that my knowledge and experience as a parent can be used to improve services for children and families.	1	2	3	4	5
26. When I need help with problems in my family, I am able to ask for help from others.	1	2	3	4	5

Table 7

Continued

27. I make efforts to learn new ways to help my child grow and develop.	1	2	3	4	5
28. When necessary I take the initiative in looking for services for my child and family.	1	2	3	4	5
29. When dealing with my child, I focus on the good things as well as the problems.	1	2	3	4	5
30. I have a good understanding of the service system that my child is involved in.	1	2	3	4	5
31. When faced with a problem involving my child, I decide what to do and then do it.	1	2	3	4	5
32. Professionals should ask me what services I want for my child.	1	2	3	4	5
33. I have a good understanding of my child's disorder.	1	2	3	4	5
34. I feel I am a good parent.	1	2	3	4	5

FES Scoring Instructions – Subscale scores are the sum of the respective item scores. Scores on the F and SS range from 12 to 60. Scores on the C/P range from 10 to 50. Higher scores reflect more empowerment.

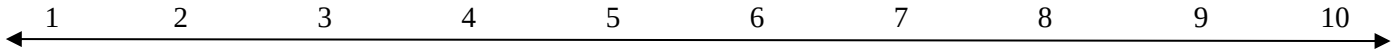
Table 8

The Multidimensional Individual and Interpersonal Resilience Measure (MIIRM)

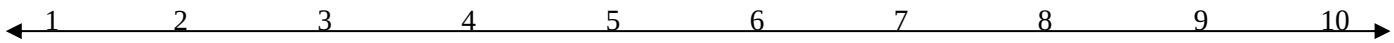
For each question below, please mark one box with your answer.

	Not True At All	**Rarely True**	**Sometimes True**	**Often True**	**True Nearly All The Time**
1. I can deal with whatever comes my way.	☐	☐	☐	☐	☐
2. I am able to adapt to change.	☐	☐	☐	☐	☐
3. I tend to bounce back after illness or hardship.	☐	☐	☐	☐	☐
4. When I am confused by a problem, one of the first things I do is survey the situation and consider all the relevant pieces of information.	☐	☐	☐	☐	☐
5. Before criticizing somebody, I try to imagine how they would feel if I were in their place.	☐	☐	☐	☐	☐
6. I sometimes find it difficult to see things from another person's point of view.	☐	☐	☐	☐	☐
7. I often have not comforted another when he or she needed it.	☐	☐	☐	☐	☐
8. Sometimes when people are talking to me, I find myself wishing that they would leave.	☐	☐	☐	☐	☐
	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
9. Overall, I expect more good things to happen to me than bad.	☐	☐	☐	☐	☐
10. I'm always hopeful about my future.	☐	☐	☐	☐	☐
11. In unclear times, I usually expect the best.	☐	☐	☐	☐	☐

12. Where do you think you stand at this time in your life, relative to other people in the United States? (People who score 10 have the most money, the most education and the most respected jobs. The higher you are, the closer you are to the people at the top).



13. In general, how satisfied are you with your finances?



Not at all Satisfied Very Satisfied

	Never	A Little of the Time	Sometimes	Frequently
14. How often do you feel lonely?	☐	☐	☐	☐
15. How often do your spouse, children, close friends and/or relatives give you advice or information about medical, financial, or family problems?	☐	☐	☐	☐
16. How often do your spouse, children, close friends and/or relatives help with daily tasks like shopping giving you a ride, or helping you with household tasks?	☐	☐	☐	☐
17. How often are your spouse, children, close friends and/or relatives willing to listen when you need to talk about your worries or problems?	☐	☐	☐	☐
18. How often do your spouse, children, close friends and/or relatives make you feel loved and cared for?	☐	☐	☐	☐
	Never	**A Little of the Time**	**Sometimes**	**Frequently**
19. How often do your spouse, children, close friends make too many demands on you?	☐	☐	☐	☐
20. How often are your spouse, children, close friends and/or relatives critical of what you do?	☐	☐	☐	☐
	Not at All	**Slightly**	**Moderately**	**Very**
21. To what extent do you consider yourself a religious person?	☐	☐	☐	☐
22. To what extent do you consider yourself a spiritual person?	☐	☐	☐	☐

MIIRM Scoring Instructions - A total score can be calculated by adding up all of the items. Higher scores indicate higher levels of resilience and lower scores indicate lower levels of resilience (Items 6, 7, 8, 14, 19, and 20 are reversed scored). Self-Efficacy (Items 1, 2, and 3), Emotional Regulation (Items 4 and 5), Optimism (Items 9, 10, 11) Emotional expression and communication (Items 6, 7, and 8 – all reversed scored), Perceived economic and social resources, (Items 12, 13, and 14 (reversed scored)), Access to support network (Items 15, 16, 17, 18), Relational Accord (Items 19 and 20 – both reversed scored), and Spirituality and Religiosity (Items 21 and 22); higher scores indicate higher levels of resilience and lower scores indicate lower levels of resilience.

Oklahoma State University Institutional Review Board

Date:	Thursday, July 07, 2016	Protocol Expires:	3/27/2017
IRB Application No:	HE1419		
Proposal Title:	Families and Intellectual and Developmental Disability: Understanding Risk and Resilience Across the Lifespan		
Reviewed and Processed as:	Exempt **Modification**		

Status Recommended by Reviewer(s) **Approved**

Principal Investigator(s):

Natalie Richardson [redacted]

Jillian Caldwell [redacted]

Samantha Johnson [redacted]

Kami L. (Schwerdtfeger) Gallus [redacted]

Jennifer L. Jones [redacted]

The requested modification to this IRB protocol has been approved. Please note that the original expiration date of the protocol has not changed. The IRB office MUST be notified in writing when a project is complete. All approved projects are subject to monitoring by the IRB.

- The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

The reviewer(s) had these comments:

Mod to add Jillian Caldwell as a Co-PI for data analysis

Signature :

Hugh Crethar, Chair, Institutional Review Board

Thursday, July 07, 2016
Date

VITA

Jillian A. Caldwell

Candidate for the Degree of

Master of Science

Thesis: PREDICTORS OF RESILIENCE IN FAMILIES OF ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES FOLLOWING DEINSTITUTIONALIZATION

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